From: mailinglist@capitol.hawaii.gov

Sent: Tuesday, February 24, 2015 5:19 PM

To: FINTestimony
Cc: Toni@a3h.org

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/24/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Toni Marie Davis	Individual	Support	No

Comments: Thank you Chair for scheduling HB782, Kulia's Bill. I had the honor of meeting Kulia and her Mom last month. I'm the mother of 3 Hawaii born babies and Auntie to many more. We will never know who and what Kulia could have, would have done had CMV been know and identified at birth. The statistics of occurrence being 1 in 150 children, equates to 130 children a year with CMV with Hawaii's current annual birth rate of 19k. This is significant. The cost of educating the public and testing (which I wish this would have stayed within the Bill - removed in HD1), I would think pales by comparison to the cost of treating the disease. Please pass this bill, similar to Utah's legislation on the same matter, to ensure our grandchildren and their children are provided maximum opportunity. It about awareness of knowledge. Sincerely, Toni Marie Davis

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

From: mailinglist@capitol.hawaii.gov

Sent: Tuesday, February 24, 2015 11:31 PM

To: FINTestimony

Cc: christinaiokia@yahoo.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/24/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
christina iokia	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Christina lokia, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Christina lokia

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From: mailinglist@capitol.hawaii.gov

Sent: Tuesday, February 24, 2015 11:34 PM

To: FINTestimony

Cc: chely.norris@gmail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/24/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Chely Norris	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Chely Norris, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Chely Norris

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From: mailinglist@capitol.hawaii.gov

Sent: Tuesday, February 24, 2015 11:28 PM

To: FINTestimony

Cc: brittcoury@gmail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/24/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Brittani Coury	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Brittani Coury, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Brittani Coury

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From: mailinglist@capitol.hawaii.gov

Sent: Wednesday, February 25, 2015 12:50 AM

To: FINTestimony jm7722@ymail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/25/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

-	Submitted By	Organization	Testifier Position	Present at Hearing
	Jessica Mathias	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Jessica Mathias, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Jessica Mathias

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From: mailinglist@capitol.hawaii.gov

Sent: Wednesday, February 25, 2015 12:48 AM

To: FINTestimony

Cc: curenmohama@gmail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/25/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Curren Ohama	Individual	Comments Only	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Curren Ohama, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Curen Ohama

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From: mailinglist@capitol.hawaii.gov

Sent: Tuesday, February 24, 2015 11:55 PM

To: FINTestimony

Cc: montoya.roxanne@gmail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/24/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Roxanne Montoya	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Roxy Montoya, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life, 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Roxy Montoya

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From: mailinglist@capitol.hawaii.gov

Sent: Wednesday, February 25, 2015 12:46 AM

To: FINTestimony
Cc: ruffatto@msn.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/25/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Donald Ruffatto	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Donald Ruffatto, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Donald Ruffatto

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From: mailinglist@capitol.hawaii.gov

Sent: Tuesday, February 24, 2015 11:53 PM

To: FINTestimony

Cc: mwloope@aloha.net

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/24/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
marshall loope	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Marshall Loope, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Marshall Loope

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From: mailinglist@capitol.hawaii.gov

Sent: Tuesday, February 24, 2015 11:52 PM

To: FINTestimony
Cc: maliaz1@yahoo.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/24/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Kristen Hirahara	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Kristen Hirahara, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Kristen Hirahara

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From: mailinglist@capitol.hawaii.gov

Sent: Wednesday, February 25, 2015 12:40 AM

To: FINTestimony

Cc: christie11mae@hotmail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/25/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
christine mae	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Christine Mae, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Christine Mae

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From: mailinglist@capitol.hawaii.gov

Sent: Tuesday, February 24, 2015 11:50 PM

To: FINTestimony

Cc: falimia43@gmail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/24/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Malia Abarra	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Malia Abarra, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Malia Abarra

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From: mailinglist@capitol.hawaii.gov

Sent: Wednesday, February 25, 2015 12:43 AM

To: FINTestimony

Cc: adelatori@yahoo.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/25/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Aulani Delatori	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Aulani Delatori, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Aulani Delatori

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

From: mailinglist@capitol.hawaii.gov

Sent: Tuesday, February 24, 2015 11:47 PM

To: FINTestimony

Cc: emerziana@gmail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/24/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
emerziana@gmail.com	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Amber Emerzian, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Amber Emerzian

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

From: mailinglist@capitol.hawaii.gov

Sent: Tuesday, February 24, 2015 11:36 PM

To: FINTestimony

Cc: samantha_shafer85@yahoo.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/24/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Samantha King	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Samantha King, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Samantha King

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From: mailinglist@capitol.hawaii.gov

Sent: Tuesday, February 24, 2015 11:38 PM

To: FINTestimony Cc: bozz808@gmail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/24/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Rosie Joe Herrnberger	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Rosie Herrnberger, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Rosie Herrnberger

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From: mailinglist@capitol.hawaii.gov

Sent: Tuesday, February 24, 2015 11:40 PM

To: FINTestimony

Cc: reynavaldez@live.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/24/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
reyna valdez	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Reyna Valdez, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Reyna Valdez

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

From: mailinglist@capitol.hawaii.gov

Sent: Tuesday, February 24, 2015 11:43 PM

To: FINTestimony

Cc: lyndseykahuhu@yahoo.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/24/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
lyndsey kahuhu	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Lyndsey Kahuhu, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life, 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Lyndsey Kahuhu

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From: mailinglist@capitol.hawaii.gov

Sent: Tuesday, February 24, 2015 11:45 PM

To: FINTestimony

Cc: javiernashley@yahoo.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/24/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Ashley McCormick	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Ashley McCormick, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Ashley McCormick

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From: mailinglist@capitol.hawaii.gov

Sent: Wednesday, February 25, 2015 9:06 AM

To: FINTestimony

Cc: tiareroberson@yahoo.ca

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/25/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Tiare Roberson	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Tiare Roberson, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Tiare Roberson

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From: mailinglist@capitol.hawaii.gov

Sent: Wednesday, February 25, 2015 8:48 AM

To: FINTestimony

Cc: tami_yamamura@yahoo.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/25/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
tami yamamura	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Tami Yamamura, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Tami Yamamura

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From: mailinglist@capitol.hawaii.gov

Sent: Wednesday, February 25, 2015 8:43 AM

To: FINTestimony
Cc: holly@a3h.org

Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/25/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Nguyen Do	Individual	Support	No

Comments:

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From: mailinglist@capitol.hawaii.gov

Sent: Wednesday, February 25, 2015 8:38 AM

To: FINTestimony

Cc: natashathorell@gmail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/25/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Natasha Thorell	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Natasha Thorell, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Natasha Thorell

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From: mailinglist@capitol.hawaii.gov

Sent: Wednesday, February 25, 2015 8:36 AM

To: FINTestimony

Cc: Nickiloren@yahoo.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/25/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted	d By	Organization	Testifier Position	Present at Hearing
Loren Mito	chell	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Loren Mitchell, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Loren Mitchell

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From: mailinglist@capitol.hawaii.gov

Sent: Wednesday, February 25, 2015 9:04 AM

To: FINTestimony

Cc: smilefab@hotmail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/25/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Fabiola Gosselin	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Fabiola Gosselin, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Fabiola Gosselin

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

From: mailinglist@capitol.hawaii.gov

Sent: Wednesday, February 25, 2015 9:01 AM

To: FINTestimony

Cc: anapuanani@yahoo.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/25/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
brandy agurrie	Individual	Support	No

Comments: Subject: SUPPORT HB 782 - Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, My name is Brandy Aguirre, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life, 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Brandy Aguirre

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

From: mailinglist@capitol.hawaii.gov

Sent: Thursday, February 26, 2015 9:09 AM

To: FINTestimony

Cc: alyssavillon@hotmail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/26/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Alyssa-Leigh Villon	Individual	Support	No

Comments: Subject: SUPPORT HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Alyssa-Leigh Villon

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

From: mailinglist@capitol.hawaii.gov

Sent: Thursday, February 26, 2015 9:17 AM

To: FINTestimony Cc: dez514@gmail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/26/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Dezaray Alexander	Individual	Support	No

Comments: Subject: SUPPORT HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Dezaray Alexander

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

From: mailinglist@capitol.hawaii.gov

Sent: Thursday, February 26, 2015 9:20 AM

To: FINTestimony

Cc: emilykoenig1@gmail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/26/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Emily Koenig	Individual	Support	No

Comments: Subject: SUPPORT HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Emily Koenig

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From: mailinglist@capitol.hawaii.gov

Sent: Thursday, February 26, 2015 8:11 AM

To: FINTestimony

Cc: Gregg.Rowe@mpd.net

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/26/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
gregg rowe	Individual	Support	No

Comments: Subject: SUPPORT HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Gregg Rowe

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From: mailinglist@capitol.hawaii.gov

Sent: Thursday, February 26, 2015 11:20 AM

To: FINTestimony

Cc: jacelynkane@hotmail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/26/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Jacelyn Kane-Simpson	Individual	Support	No

Comments: Aloha Honorable Members of The House Committee on Finance, Subject: HB 782 Regarding Cytomegalovirus Education and Early Intervention My name is Jacelyn Kane-Simpson, Kulia's Aunty and a mother of 3. I am in support of HB782. I humbly ask for your support in the passing of this bill. I humbly ask for you support and consideration to have it renamed to Kulia's Bill and to re-instate the mandated testing of newborns upon 2 failed hearing screenings. Education is the most important part of this bill. I understand the legality of not being able to implement mandated testing and treatment for newborns by Physicians. But the mandated screenings are very important to the early detection and treatment to prevent severe effects of a newborn that was born with CMV. If this cannot be done at this time will you please consider to have the education section revised to include information on screenings and treatments available to newborns? What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down Syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. Early intervention and treatment of affected newborns is the next step to lessening the financial burden to the State of Hawaii. Numerous studies have shown that, early treatment for CMV as a newborn may improve hearing loss, head size, brain growth and benefit the child's developmental milestones. If a child goes undetected or untreated, side effects that could have been lessened or improved will gradually get worse. For example, mild CMV hearing loss at birth, with no treatment may gradually lead to decreased hearing loss and possible bilateral cochlear implants that cost about \$120,000. If the prevention program prevents one child from getting them, that is a significant savings(especially if the child gets them paid for by Medicaid, which is usually the case) Utah's cost to start up a successful CMV education program was \$30,800 according to Sara Dourte, aradoutre@gmail.com member of the team responsible for Utah's CMV Public Health Initiative legislation and cofounder of the Utah CMV Council. Keep in mind this cost includes researching and creating all documents that are available to Hawaii for free. Easy to create simple Hawaii CMV education brochures found at: http://www.health.utah.gov/cshcn/CHSS/CMV.html Hawaii can replicate Utah's congenital CMV education and marketing materials, such as its brochure for

childcare providers and legal documents, by replacing Utah's Department of Health logo with Hawaii's Department of Health logo. Contact: Stephanie Browning McVicar, Au.D., CCC-A, State EHDI Director, State of Utah DOH, (801) 584-8218 smcvicar@utah.gov Utah has already put up the cost to develop a webpage and all necessary documents for a successful program here in Hawaii. The department of Health in Utah is more than willing to help Hawaii to help address CMV. See attached documents. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. The annual average cost of caring for children disabled by congenital CMV in a state can be calculated as follows: (annual births X .0013 X 200000 = \times) in Hawaii (2013) 18,826 births X .0013 disabled by congenital CMV = 24.47 children X \$200,000 = 4.894 million. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an nderestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Hawaii can reduce the suffering and financial burden caused by congenital CMV by spending money up front to decrease the incidence and severity of CMV infection, which will be a smart financial decision, as in the end it will the save DOH, public and Hawaii's families money and more importantly newborns their opportunities to thrive in life. When you find out your expecting you think oh my gosh I want a girl or I want a boy. Then you think I just want a healthy child. You go to your first OB-GYN appointment, you read articles you see flyers and brochures about Down Syndrome, the effects of drug and alcohol use while pregnant. You don't hear about CMV - Cytomegalovirus. But what happens if you contract this virus while pregnant? What happens when your child goes undiagnosed for months? Education and awareness and screenings will prevent future babies from having to go thru what Kulia and her family has been going through and will continue to go through for the rest of their lives. Awareness and education and testing after 2 failed hearing screenings could have prevented Kulia from the severity of what CMV has done to her little brain and body. Kulia is an inspiration to me and my family and will continue to be. She is a beautiful happy child surrounded by love. We will continue to support Kulia and her families efforts to make HB782 a reality. We will continue to support her fight to help others. Please feel free to contact me via email or by telephone for any question you have. Mahalo Nui Loa, Jacelyn Kane-Simpson 808-419-1221 jacelynkane@hotmail.com

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From: mailinglist@capitol.hawaii.gov

Sent: Thursday, February 26, 2015 9:08 AM

To: FINTestimony

Cc: kotake76@gmail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/26/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Kendra Otake	Individual	Support	No

Comments: Subject: SUPPORT HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Kendra Otake

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

From: Krystyn Aguinaldo <krystynjames@gmail.com>

Sent: Thursday, February 26, 2015 2:37 PM

To: FINTestimony

Subject: Fwd: Lisa Lareau 782

Sent from my iPhone

Begin forwarded message:

From: Krystyn Aguinaldo < krystynjames@gmail.com>

Date: February 26, 2015 at 2:36:34 PM HST

To: Krystyn Aguinaldo <krystynjames@gmail.com>

Subject: Re: Lisa Lareau 782

From: "Shakasoap@gmail.com" <shakasoap@gmail.com>

Date: February 26, 2015 at 8:24:50 AM HST

To: Krystyn Aguinaldo < krystynjames@gmail.com>

Subject: SUPPORT HB 782 – Cytomegalovirus Initiative (Kulia's Bill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing **HB 782** – **Relating to the Cytomegalovirus**.

What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone.

According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's

children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program.

Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782.

Thank you very much,

Lisa Lareau

Lisa Lareau Lisa@shakastreet.com

From: mailinglist@capitol.hawaii.gov

Sent: Thursday, February 26, 2015 9:14 AM

To: FINTestimony

Cc: Iparanada808@hotmail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/26/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Lynelle	Individual	Support	No

Comments: Subject: SUPPORT HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Lynelle Paranada

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From: mailinglist@capitol.hawaii.gov

Sent: Thursday, February 26, 2015 8:13 AM

To: FINTestimony

Cc: meganluana@gmail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/26/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Megan Bouhey	Individual	Support	No

Comments: Subject: SUPPORT HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Megan Bouhey

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From: mailinglist@capitol.hawaii.gov

Sent: Thursday, February 26, 2015 8:18 AM

To: FINTestimony

Cc: nola96753@yahoo.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/26/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Nola Jean Rowe	Individual	Support	No

Comments: Subject: SUPPORT HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Nola Jean Rowe

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

From: mailinglist@capitol.hawaii.gov

Sent: Thursday, February 26, 2015 9:12 AM

To: FINTestimony

Cc: rachel.1982@yahoo.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM

HB782

Submitted on: 2/26/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Rachel Garvin	Individual	Support	No

Comments: Subject: SUPPORT HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 - Relating to the Cytomegalovirus. What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone. According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program. Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782. Thank you very much, Rachel Garvin

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<u>Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill)</u>

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see http://www.cdc.gov/cmv/index.html)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it.

I am a cousin of Krystyn Aguinaldo and have been watching Kulia's story unfold. It is a powerful, heartbreaking and loving story. The immediate family as well as the extended family has embraced Kulia. The overwhelming support from the family and extended family has been indescribably incredible. There is so much love for this beautiful little girl, Kulia. However, this family will be forever changed, due to lack of prevention education and newborn testing criteria. When such a simple lab test as well as action on a 2 nd failed hearing test, could have prevented the progression of a debilitating condition. I do not know the cost of the test; however, the cost of this test should not overbear the health of life. I look around at my children, my grandchildren as I'm sure you can look to yours. Imagine how different life would be with such a lifelong hardship. You may have other hardships that bear equal weight. However, if such a hardship can be avoided, then shouldn't this be a simple decision to pass a bill to make CMV testing available to newborns and to enact an education prevention program to all pregnant women? Kulia's story will go on, however, be a part of that story to pass the bill that can impact the lives of many! Be the person to make a change today, please pass this bill!

Mahalo.

Sherri Sandona Kamenski, CIT, RN, CST Senior Application Analyst ssandona@columbia-stmarys.org

finance8-Melanie

From: Krystell Carcamo <krystellewellie@yahoo.com>

Sent: Friday, February 27, 2015 10:22 AM

To: FINTestimony
Subject: Please pass HB 782

LATE

Please pass HB 782

Thank you, Krystell Carcamo Sent from my iPhone

finance8-Melanie

From: Rita Kahaialii <ritakahaialii@gmail.com> Sent: Friday, February 27, 2015 11:19 AM

To: FINTestimony Subject: Kulia's HB 782



Aloha,

I am writing to you requesting that you pass Kulia's HB 782, so other moms and the future keiki of our island may live happy, healthy and normal lives.

Mahalo

From: mailinglist@capitol.hawaii.gov
Sent: Friday, February 27, 2015 9:11 AM

To: FINTestimony
Cc: rusty.iokia@mpd.net

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00AM



HB782

Submitted on: 2/27/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Rusty lokia	Individual	Support	No

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia'sBill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you for your support of HB 782 – Relating to the Cytomegalovirus. Congenital cytomegalovirus (CMV) is a known cause of severe to profound hearing loss in children. As an Audiologist for over 20 years, I have seen the devastating effects of this disease. Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 assist in preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. Mahalo, Rusty B. lokia. Kulia's father

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

From: mailinglist@capitol.hawaii.gov
Sent: Friday, February 27, 2015 9:17 AM

To: FINTestimony

Cc: stacelynn84@gmail.com

Subject: Submitted testimony for HB782 on Feb 27, 2015 11:00A



HB782

Submitted on: 2/27/2015

Testimony for FIN on Feb 27, 2015 11:00AM in Conference Room 308

Submitted By	Organization	Testifier Position	Present at Hearing
Stacelynn	Individual	Support	No

Comments: The education, early identification and newborn screening proposed in this measure will save lives

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

DAVID Y. IGE GOVERNOR OF HAWAI



VIRGINIA PRESSLER, M.D.
DIRECTOR OF HEALTH



P. O. Box 3378 Honolulu, HI 96801-3378 doh.testimony@doh.hawaii.gov

Testimony COMMENTING on H.B. 782, H.D. 1 RELATING TO CYTOMEGALOVIRUS

REPRESENTATIVE SYLVIA LUKE, CHAIR HOUSE COMMITTEE ON FINANCE

Hearing Date: February 27, 2015 Room Number: 308

1 **Fiscal Implications:** H.B.782, H.D.1 provides an unspecified appropriation in general funds to the Department of Health (DOH) for fiscal year 2016-2017 to implement this public awareness program 2 on Cytomegalovirus (CMV) to educate and inform pregnant women and women who may become 3 pregnant. The DOH will need one full-time coordinator position to convene the working group of 4 5 various stakeholders to participate in the development of a public awareness program to inform and 6 educate pregnant women and women who may become pregnant about CMV; and to submit a report 7 that includes recommendations for developing, implementing, and funding the public awareness 8 program to educate and inform pregnant women and women who may become pregnant. The DOH 9 is not able to conduct this program within existing resources. The recommendations in the report would determine the appropriation then needed to implement the CMV public awareness 10 recommendations. 11 12 **Department Testimony:** The Department appreciates the intent of this bill, but defers to the Governor's Executive Budget request and the Department of Health's appropriations and personnel 13 priorities. 14 The U.S. Centers for Disease Control and Prevention (CDC) estimates that about 50%-80% 15 of adults in the US are infected with CMV by the time they are 40 years old. The virus is generally 16 passed from infected people to others through direct contact with bodily fluids such as urine and 17

of adults in the US are infected with CMV by the time they are 40 years old. The virus is generally passed from infected people to others through direct contact with bodily fluids such as urine and saliva. For pregnant women, the two most common exposures to CMV are through sexual contact and through contact with the urine and saliva of young children with CMV infection. Most healthy children and adults infected with CMV have no symptoms. About 1 to 2 babies out of 1000 births may have permanent CMV-related problems.

- 1 A woman getting infected with CMV while pregnant increases the chance of having an infant with
- 2 congenital CMV. However, since the virus is so pervasive in the environment, it would be very
- 3 difficult to prevent infection with an educational process.
- The recommendations on the National Institutes of Health website on congenital CMV
- 5 http://www.nlm.nih.gov/medlineplus/ency/article/001343.htm:
- 6 "Cytomegalovirus is almost everywhere in the environment. CDC recommends the following steps to
- 7 reduce the spread of CMV:

8

9

- Wash hands with soap and water after touching diapers or saliva.
- Avoid kissing children under the age of 6 on the mouth or cheek.
- Do not share food, drinks, or eating utensils with young children."
- 11 Thank you for the opportunity to testify.



From: Oni Boi <pilotoniboi@gmail.com>
Sent: Friday, February 27, 2015 5:45 AM

To: FINTestimony Subject: Please pass HB 782

Hello,

I am emailing to ask that HB 782 be passed. I believe it is for the best and everyone (mommies & babies) that does test positive will only benefit from it. Treating anything in the early stages always has a better chance of working, even if just a little. Little can make a huge difference.

Thanks so much,

Emma Javellana

From: maggirose28 < maggirose28@gmail.com>

Sent: Friday, February 27, 2015 2:14 AM

To: FINTestimony Subject: pass HB 782



I am so proud of my Maui family making things happen. I greatly ask that you pass HB 782. it is needed. Thank you for listening to me.

With great thanks, Maggie Rose Viernes

Sent from my T-Mobile 4G LTE Device

From: Alena <alenaksmith@gmail.com>
Sent: Friday, February 27, 2015 8:09 AM

To: FINTestimony Subject: Kulia's bill



I'm in full support HB 782 Kulia's bill. I believe there should be more education on cmv. I am a mother of two and wasn't even aware of the common virus. I also believe there should be actions taken to help newborns who might've come in contact with the virus.

Mahalo Alena Herbias

Sent from my iPhone

From: Trisha Dinson < kawehalani@gmail.com>
Sent: Friday, February 27, 2015 8:15 AM

To: FINTestimony Subject: Kulia's Bill



To Whom It May Concern,

I support Kulia's Bill. Please pass this bill. It is imperative for mother's to take precautions for our precious babies.

Mahalo,

Trisha Dinson

From: Krystyn Aguinaldo < krystynjames@gmail.com>

Sent: Friday, February 27, 2015 1:28 AM

To: FINTestimony Subject: HB 782 SUPPORT

Sent from my iPhone

Begin forwarded message:

From: Krystal Calibuso < <u>kcalibuso 04@gmail.com</u>>

Date: February 26, 2015 at 5:51:50 PM HST

To: Krystyn Aguinaldo < krystynjames@gmail.com >



Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing **HB 782** – **Relating to the Cytomegalovirus**.

What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone.

According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program.

Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782.

Thank you very much,

Krystal Calibuso

1



From: Krystyn Aguinaldo <krystynjames@gmail.com>

Sent: Friday, February 27, 2015 1:32 AM

To: FINTestimony Subject: HB 782 SUPPORT



From: Raina deVault < <u>raina.devault@gmail.com</u>>

Date: February 26, 2015 at 5:07:38 PM HST

To: Krystyn Aguinaldo

Subject: SUPPORT HB 782 – Cytomegalovirus Initiative (Kulia's Bill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing **HB 782** – **Relating to the Cytomegalovirus**.

What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone.

According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program.

Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782.

Thank you,

Raina deVault Makawao, HI Raina.devault@gmail.com



Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see http://www.cdc.gov/cmv/index.html)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable, but only if women know about it.

I strongly support Bill HB 782 for CMV awareness and CMV education for all pregnant women and physicians.

I first learned about CMV in a virology course in college where it was briefly explained. It was until I started work in the Houston CMV research laboratory that I learned of the unnecessary and devastating effects the virus has on the unborn fetus.

Please help save unborn babies from this silent disease by spreading awareness and educating the community about preventive measures.

Sincerely,

Cindy De Los Santos Houston CMV Research Baylor College of Medicine Texas Children's Hospital

From: Krystyn Aguinaldo <krystynjames@gmail.com>

Sent: Friday, February 27, 2015 1:34 AM

To: FINTestimony Subject: HB 782 SUPPORT



Sent from my iPhone

Begin forwarded message:

From: Kay < hawaiiangirlz 13@yahoo.com > Date: February 25, 2015 at 8:53:14 PM HST

To: Krystyn Aguinaldo krystynjames@gmail.com

Subject: HB 782

Subject: SUPPORT HB 782 – Cytomegalovirus Initiative (Kulia's Bill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto,

Aloha my name is Kaylen Mahuka. I am writing this letter in behalf of Kulia Iokia in supports of Kulia's Bill HB 782. I am a close friend of her Aunty Donnette whom is a sister of Kulia's Father. When I heard the tragic news of Kulia's condition it broke my heart. As a mother I can feel for Kulia and her Ohana because it could've been prevented by conducting just one test. But moving forward I follow Kulia closely on Instagram and Facebook and I see her progress and I pray for this baby girl that she gets better by the day. I commend Krytyn and Rusty for their push in creating this bill to prevent any other babies and families to have to go through this. I pray that Hawaii's legislators approve of Kulia's Bill and make it not just statewide but nationwide to help with the prevention and to educate parents to be of what CMV is. When I had my third pregnancy I asked my OB if I should check for it but she said no. I would like to see it be a requirement in pregnancies and after birth shall the newborn fail their hearing test. Mahalo for accepting my letter and I pray that Kulia's Bill HB 782 is approved.

Kaylen Mahuka 808-699-1916

<u>Subject: HB 782 — Cytomegalovirus Initiative (Kulia's Bill)</u>

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,



I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB –Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see http://www.cdc.gov/cmv/index.html)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it.

I have had the pleasure of knowing Krystyn and Kulia. Before this I hadn't even heard the term CMV. I know so much more now than I ever did. I know that education and early detection is key. I to have a daughter with special needs. I know what it is like to be helpless and not being able to do anything to help your child. Don't let this happen to anyone else. Pass Kulia's bill so that what happened to Kulia doesn't happen to someone else's child. If this was your child, wouldn't you want to be educated?

Mahalo,

Coty Luke

cotyluke@gmail.com 808-269-4664



MCV Hospitals and Physicians

Department of Microbiology and Immunology 1101 E. Marshall Street Sanger Hall, Rm 12-051 Richmond VA 23298-0163

Tel: 804-828-1807 Fax: 804-827-0575 sadler@vcu.edu

Stuart P. Adler Professor of Microbiology, Emeritus Professor of Pediatrics and Chairman Division of Infectious Disease



February 7, 2015

Dear Sirs:

I write to support Hawaii CMV Bill HB 782, which would establish a newborn screening program for cytomegalovirus and develop a public education program regarding the dangers of congenital CMV and the methods of prevention of CMV.

I have studied this topic as an investigator for many years and know that prevention of maternal infection with CMV is in most cases easily preventable using hygienic intervention, if only women were aware of CMV, its effects on the fetus, and how to reduce their risk of infection.

This bill also directs medical practitioners to test infants, for whom hearing tests indicate hearing loss, for CMV and inform the parents of those infants about the possible birth defects that CMV can cause as well as any appropriate interventions. The Utah state legislature unanimously passed similar legislation (HB81), which is currently being implemented by their Department of Health.

The hearing aspect of the bill is also important. Hearing deficit is common after a CMV infection before birth. Numerous studies have shown that are multiple means of post-natal intervention that reduce or eliminate the consequences of deafness, particularly speech development.

I urge you to approve this legislation.

Thank for your consideration.

Sincerely,

Stuart 19. Adler

Stuart P. Adler M.D.



From: Krystyn Aguinaldo <krystynjames@gmail.com>

Sent: Friday, February 27, 2015 1:39 AM

To: FINTestimony Subject: HB 782 SUPPORT

Sent from my iPhone

Begin forwarded message:

From: Krystyn Aguinaldo < krystynjames@gmail.com >

Date: February 5, 2015 at 11:33:58 AM HST

To: Krystyn Aguinaldo krystynjames@gmail.com>

Subject: Jacy Corwin letter 782

Sent from my iPhone

On Feb 5, 2015, at 8:58 AM, Jayci Corwin < <u>icorwin@hhsc.org</u>> wrote:

Subject: HB 782 – Kulia's Bill Cytomeglarovirus

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see http://www.cdc.gov/cmv/index.html)

While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill

1

creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

Thank you,

Jayci Corwin
Kihei, HI
jaycicorwin@msn.com

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February 16, 2015

Re: SUPPORT FOR H.B. #782 Relating to the Cytomegalovirus

Dear Honorable Representatives:

Please pass this important legislation so women will know about simple precautions to take during pregnancy to prevent devastating birth defects and so that newborns who are infected with CMV can have treatment to prevent and treat devastating birth defects.

In early 1990 my husband and I were enjoying our 17-month old son and looking forward to the birth of our daughter. My obstetrician tested me for CMV early in the pregnancy but did not tell me anything about CMV or that I was CMV seronegative (*i.e.*, I had never had the virus before). I should have been told that women who contract CMV for the first time when they are pregnant can pass multiple profound life-long disabilities to their unborn children and that I could massively reduce this risk with simple precautions such as not kissing toddlers on the mouth, not sharing food from my plate or fork with other people and sticking to good hand-washing habits. This information was not provided to me. As a result, I was ignorant of CMV and my baby was vulnerable to its devastation. Simple counseling could have prevented the odyssey I am about to describe. An ounce of prevention could have saved a pound of cure.

A sudden weight gain when I was about 32 weeks into the pregnancy led to an ultra sound that revealed the baby's abdomen was severely bloated with fluid. I was referred to a high-risk obstetrician who, through testing of a fetal blood sample, gave our family the diagnosis and grim prognosis of severe symptomatic CMV. We consulted many experts who all warned us of death and/or multiple severe handicaps and painful conditions for our baby.

Although it is impossible to describe how my husband and I felt, I can say we were in a pit of despair and we grieved for our daughter before she was even born. We were distressed about the toll our constant absence at appointments and emotional turmoil would take on our son, still in diapers.

Our high-risk obstetrician told us about the in-utero therapy available at the time to improve the prognosis. Twice he performed a procedure to drain the fluid in our unborn baby's abdomen with an amnio needle that penetrated first my skin, then the baby's. The procedures were not painful to me and both enabled my body to

carry the baby to 35 weeks when the already severe problems would not be compounded by extreme prematurity and reduced the pressure the fluid was causing on all of the baby's still-developing organs.

Just a few short weeks after we first heard of CMV, our daughter was born. She had petechiae all over her body, an enlarged liver and spleen, kidney disease, and swelling of the brain. One doctor advised me not to bond with my daughter because she would die shortly.

We received mostly bad news during the first week of her life, and I remember being so weak and grief stricken, barely able to stand by her incubator looking at that poor little sick baby and thinking about what life would be like for her.

But our high-risk obstetrician referred us to his colleague at the Baylor College of Medicine, Dr. Gail Demmler-Harrison, a CMV expert. I will never forget sitting in Dr. Demmler's office with my husband five days after our daughter's birth and having her tell us "there is hope". Dr. Demmler told us about the experimental ganciclovir study. Only 15 babies had ever been treated with ganciclovir, and all in the previous six months. Our daughter would be the first baby in Houston to receive the treatment. Improved outcomes were seen in the previous 15 babies, but at that point the experts thought a higher dose was needed for real effectiveness. Dr. Demmler also told us about therapies available for the many conditions our daughter could have as a result of the CMV.

Over the next three weeks, our daughter continued to be very ill, was not gaining weight, was shedding high levels of the virus and there were pockets of the virus in her brain with evidence of some calcifications. It appeared that her brain damage was in fact minimal at this point but if the disease progressed severe damage would happen. A medical situation like we were in has cascading repercussions to all members of the family and all aspects of life. Emotional, financial, spiritual and other forms of upset came to our family, but we were offered and accepted help that ranged from meals from neighbors to the doctors' explaining to our insurance company the necessity of the experimental treatment for our daughter that we were soon to embark on.

Within days of starting the ganciclovir treatment, our daughter started smiling, took a bottle with gusto, gained weight, healed from all of the conditions the disease had been ravaging on her little body, and the virus became undetectable in her system. There were no ill side effects from the drug, except for a brief drop in her white blood count. Our daughter went through many tests during her hospital stay and after, but the only problem that was revealed was her deafness. After

everything that had happened, we really were celebrating. I don't mean to minimize the hardship and challenges that being deaf has brought to our daughter's life, but to escape severe symptomatic congenital CMV with only that problem is something we are thankful for.

Our daughter has diligently gone for follow-up exams for the CMV and ganciclovir studies her entire life. Her brother volunteered as a control subject around the age of 13 and went for intensive annual testing.

At the age of 14, our daughter underwent cochlear implant surgery on her left side. While the implant gives her some hearing, the surgery comes with risks and can take over four hours. It is not a simple outpatient procedure that some people believe it to be.

Our daughter is now 24 years old, has an amazing compassionate heart for other people, is a college graduate and has embarked on a career. Intervention during my pregnancy and early in her life saved her life and spared her from other severe and painful conditions.

But, if I had had proper counseling early in my pregnancy like all women should, I could have taken simple precautions that would have prevented my infection with CMV, her deafness and all of the medical therapies and special training she has endured. I can hardly believe that a quarter-century after our CMV story began, women are still not being told about CMV prevention and therapies.

PLEASE PASS THE BILL!

Sincerely,

Jenny Meeden Bailey

P.O. Box 1758, Blanco, Texas 78606

Jmb1553@gmail.com



From: Krystyn Aguinaldo < krystynjames@gmail.com>

Sent: Friday, February 27, 2015 1:43 AM

To: FINTestimony Subject: HB 782 SUPPORT

Subject: Gabi Kanoa

From: Gabi Kanoa < gabikanoa@yahoo.com > Date: February 16, 2015 at 6:57:47 PM HST

To: "krystynjames@gmail.com" < krystynjames@gmail.com>

Subject: Kulia Bill

Reply-To: Gabi Kanoa < gabikanoa@yahoo.com >

Dear Local Senate.

Hello, my name is Gabriella Kanoa. I am an eighth grader currently attending Kamehameha Schools Maui. You are probably wondering, "Why is an eighth grader writing to you?" Well... there is a serious problem that I wish to fix; that is Congenital Cytomegalovirus. Congenital Cytomegalovirus is when a virus infects an infant before birth. My cousin recently got a big hand scoop of the infection, and she changed my view of life.

On August 23, 2013, my baby cousin, Kulia, was born. We saw no signs of any virus in her. She looked like a completely ordinary baby, but we were all wrong.

If only we could have stopped it from destroying her for 5 months before she was diagnosed. If only we took the test to see if baby Kulia had a virus before. There are many ifs, but nothing can change the past. She smiles every time I see her, and I think to myself *she looks normal, but deep down inside the little brain of hers is the remaining's of the holocaust that she had to fight her way through*. I do not want to see another baby go through the pain that Kulia is experiencing.

About 30,000 children are born with this nasty virus each year in the United States. Many children get disabilities because of this virus. Some of the syndromes that children get are Down syndrome, Fetal Alcohol Syndrome, Spina Bifida, and Pediatric HIV/AIDS. Sometimes there are no symptoms that show if a newborn has Congenital CMV, sometimes they are obvious signs and most times they fail hearing screenings, as my baby cousin did. Kulia failed 4 hearing tests, not even that promoted a test.

Now that I have explained my idea, I plead to you to do your part and help me through this. I wish for you to make a law to enable all pregnant women to be educated on this brutal Cytomegalovirus. One day I would like to be the next great writer or a health scientist finding a vaccine to help pregnant mothers and babies, I know this is in the future. In the present I ask for you all to at least try for Aunty Krystyn, Kulia, and me. We can change lives by just educating and we can save lives by taking one easy test. I understand that *I am* just an eighth grader, and I am just starting to learn about these things, but if this law does not get passed many women will not be educated therefore more babies will get CMV and go undetected and

1

untreated. The main thing is that I have tried my best. I will continue to try and try throughout my whole life. Thank you for taking the time to read this letter. I hope you consider everything I have written.

Sincerely, Gabriella Kanoa From: Krystyn Aguinaldo <krystynjames@gmail.com>

Sent: Friday, February 27, 2015 1:44 AM

To: FINTestimony Subject: HB 782 SUPPORT

From: Jennifer Blohm < jennblohm@gmail.com >

Date: February 8, 2015 at 6:45:33 PM HST

To: krystynjames@gmail.com
Subject: My letter for HB 782

Subject: **HB 782** – Cytomegalovirus Initiative (Kulia'sBill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to endorse and pass **HB 782** – **Relating to the Cytomegalovirus (CMV)**. CMV impacts families in devastating ways and because the brain and bodily damage to infants can be prevented with proper testing early on, I urge you to support this bill.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.(see http://www.cdc.gov/cmv/index.html)

Unlike most disabilities, **CMV** is **preventable**. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. Please help us to do something about it for future children in Hawaii.

Mahalo,

Jennifer Blohm

jennblohm@gmail.com 808-594-0061



From: Krystyn Aguinaldo < krystynjames@gmail.com>

Sent: Friday, February 27, 2015 1:44 AM

To: FINTestimony Subject: HB 782 SUPPORT

From: Kaulana Iokia < kaulanak@gmail.com >

Date: February 7, 2015 at 2:29:36 PM HST

To: Krystyn Aguinaldo < <u>krystynjames@gmail.com</u>>

<u> Subject: HB 782 - Cytomegalovirus Initiative (Kulia's Bill)</u>

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and

Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see http://www.cdc.gov/cmv/index.html)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it.

Kulia is my niece, and has been a blessing in our family with her bubbly personality. From the day she was born, she has been the light of her

family. Though it is heartbreaking to learn that so much of this could have been prevented, by taking such small steps.

We know that the greatest life lessons can be learned from our past. We hope that Kulia's experience will be the changing point from here on. We need to do more to help children and families, and Kulia's family is striving to help make a positive impact on the future.

Please work with other legislators to hear the voice of the children. We need your help and support, so that the future of our children can continue to be protected. Life hinges on small decisions made daily.

Mahalo,

Andrew lokia

premier.flooring.company@gmail.com



From: Krystyn Aguinaldo < krystynjames@gmail.com>

Sent: Friday, February 27, 2015 1:45 AM

To: FINTestimony Subject: HB 782 SUPPORT

Sent from my iPhone

Begin forwarded message:

From: erwin domingo < erwin57domingo@gmail.com>

Date: February 13, 2015 at 9:23:24 PM HST

To: Krystyn Aguinaldo <krystynjames@gmail.com>

Subject: Fwd: HB 782 Kulias bill hearing

----- Forwarded message -----

From: "erwin domingo" < erwin57domingo@gmail.com>

Date: Feb 13, 2015 9:20 PM

Subject: HB 782 Kulias bill hearing To: repcreagan@capitol.hawaii.gov

Cc:

Hello Representative Nishimoto, my name is Erwin Domingo and I am a good friend of Kulia's mother Krystyn Aguinaldo.

I have a child who has spina bifida and I could only imagine what she is going through right now. Not being able to help your child feels helpless because all you can do is just watch and try and put on a smile when deep inside its killing you. I know that Kulia isnt in the same state of my child, but no parent should be going through life with having to worry about if they can and will be normal again. My point is, more people need to be aware of not just Kulia's defects, but others that affect everyones daily life. And what Krystyn is doing is a start to something, better than just waiting and expecting for a miracle to happen.

I support Krystyn in what she is fighting for. The right to be heard! And therefore I support Kulia's cause. Every child needs a chance in life, dont you think so? Erwin



From: Krystyn Aguinaldo <krystynjames@gmail.com>

Sent: Friday, February 27, 2015 1:46 AM

To: FINTestimony Subject: HB 782 SUPPORT

From: Sue Krabisch < suziemarie 2007 @ yahoo.com >

Date: February 10, 2015 at 11:01:09 PM HST

To: Krystyn Aguinaldo < <u>krystynjames@gmail.com</u>>

Subject: Letter for Kulia's Bill

Reply-To: Sue Krabisch < <u>suziemarie2007@yahoo.com</u>>

Subject: HB782- Cytomegalovirus Initiative – Kulia's Bill

Dear Honorable Representatives and Senators of the State of Hawaii,

I am writing to ask you to please help children like Kulakahemolele who have needlessly suffered from CMV. Not only will you be saving the future of our children, you will be saving parents a lifetime of watching their children struggle in a world they should be enjoying by running, laughing and just being healthy children. You will also be saving the State of Hawaii as well as parents time and money by supporting and passing the HB782 bill – Kulia's Bill. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see http://www.cdc.gov/cmv/index.html)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save our children and their parents from needless suffering and endless medical bills as well as saving Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it.

In this day and age our children should not be suffering from diseases like CMV, cancer, muscular dystrophy, cerebral palsy and an endless list of diseases. Needless to say our children are our future and what kind of future do any of us have if we can't save our children from a disability like CMV. I am saddened at how many children I see suffering from disabilities today and I have met and befriended two wonderful people in my lifetime who have been disabled by CMV however, I thought this was a disability that was under control and that ALL children today were screened at birth. Both of the people I know were born in the 60's and lived their lives with cerebral palsy. I can understand that back in the 60's testing may not have been available, but today this should not be happening.

We, as parents rely on our doctors being educated enough to recognize a problem when a child fails a test, not send them home and say all is well. That is what happened to Kulia, she failed her hearing test not once, not twice but three times and wasn't tested again until four months later when it was too late to fight off this virus.

Please pass this bill so that all expectant mothers, families, health care providers, schools, day care centers and clinics along with requiring, by law, that a new born be tested for CMV if a hearing test is failed at birth and again before leaving the hospital.

Mahalo for your attention to this urgent matter at hand.

Susan M. Krabisch
A blessed single parent to a healthy child
Suziemarie2003@gmail.com
Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and
Representative Della Au Belatti



From: Marlene Vidal <marleneroldan@gmail.com>

Sent: Friday, February 27, 2015 6:14 AM

To: FINTestimony
Subject: HB 782- Kulia's Bill

To Whom it May Concern,

My name is Marlene Roldan and I reside in Pukalani, Maui. I humbly ask to pass HB 782, Kulia's Bill. I am a mother of two and plan to have more children in the near future. I also know Kulia and her ohana and what we are fighting for is nothing more than awareness for the safety of our islands keiki. Please, please shed some lig ht and pass Kulia's Bill. The keiki are our future. This is a major way to show them they are.

Mahalo for taking the time to read my plea.

Sincerely,

Marlene Roldan 226A Ehilani St 96768

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Sent from Marlene's iPad



From: Sierra Duarte <sduarte93@yahoo.com> Sent: Friday, February 27, 2015 7:09 AM

To: FINTestimony
Subject: HB 782 Kulias Bill

I support this bill so please pass Kulias Bill HB 782!

Sincerely, Sierra Duarte Sent from my iPhone

LATE

From: Rose Pisarski <rpisarski@allensplumbinghi.com>

Sent: Friday, February 27, 2015 7:48 AM

To: FINTestimony Subject: HB 782 KULIAS BILL

To Whom It May Concern:

I really want to see this bill passed. So thankful to Krystyn Aguinaldo for opening my eyes to the world of CMV. I just recently had a baby and I can't imagine being a parent going through what they did. Please pass this bill so that other babies can receive help they need before its to late.

Rose Pisarski - Administrator

Tel #: 808-877-6370 / Fax #: 808-877-4657 Email: Rpisarski@allensplumbinghi.com Website: www.allensplumbinghi.com





From: Krystyn Aguinaldo <krystynjames@gmail.com>

Sent: Friday, February 27, 2015 1:42 AM

To: FINTestimony Subject: HB 782

From: Kuualoha Makamai < kuualoha 77 @yahoo.com>

Date: February 16, 2015 at 6:37:19 PM HST

To: Krystyn Aguinaldo <<u>krystynjames@gmail.com</u>>

Subject: Re: Measure Status HB782

Subject: HB 782 – Kulia's Bill Cytomeglarovirus

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour.

(see http://www.cdc.gov/cmv/index.html)

While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth

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defects and disabilities caused by CMV.

As a mother of three handsome and healthy boys, ages 9 years, 5 years, and 2 years, CMV is something that I would have liked to know more about during my pregnancies. While I am grateful that my sons and I were not affected by CMV, I would have been devastated if I had passed it on to them without knowing that I could have or that it could have been prevented. According to a CDC: CMV Preventable Flyer, one preventable measure is to limit close contact with children younger than 2 and a half years old, especially if you've never been infected with CMV or didn't know if you've been infected. This hits home for me because my middle was 2 months shy of being 2 and a half years old when I found out I was pregnant to my youngest son. Not knowing that he could have passed something on to me that could have been passed on to his baby brother would have been devastating. My youngest son was born six weeks early due to severe preeclampsia which I also had no clue about until I was hospitalized with it for three weeks. It saddens me that after four pregnancies and three sons, Kulia's battle with CMV is the first that I am hearing about it. To know that many of the struggles that Kulia and her 'Ohana face on a daily basis could have been prevented breaks my heart and makes me furious that there are no standards or laws when it comes to testing for CMV! Perhaps if there was a standard for testing for CMV things would be different for Kulia and her 'Ohana. If something as devastating as CMV can be prevented why would anyone want to keep those facts from pregnant women? Why isn't there more information out and available? Why don't more doctors or nurse practitioners discuss it with their pregnant patients?

Thank you,
Harmony Brede
Waianae, HI
Mother, Substitute School Health
Aid kuualoha77@ yahoo.com



From: Krystyn Aguinaldo <krystynjames@gmail.com>

Sent: Friday, February 27, 2015 1:36 AM To: FINTestimony; Krystyn Aguinaldo

Subject: HB 782

Sent from my iPhone

Begin forwarded message:

From: Krystal Loui < krys_anu@hotmail.com > Date: February 25, 2015 at 6:22:45 PM HST

To: "krystynjames@gmail.com" < krystynjames@gmail.com>

Subject: Letter

<u>Subject: SUPPORT HB 782 – Cytomegalovirus Initiative (Kulia's Bill)</u>

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Finance Committee Members, Chair Luke, and Vice Chair Nishimoto,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing **HB 782** – **Relating to the Cytomegalovirus**.

What is congenital Cytomegalovirus (CMV)? The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. Yes, it's that common and easily transmitted. According to the CDC: Every hour, congenital CMV causes one child to become disabled. Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year) About 1 in 5 of congenitally infected children is permanently disabled. Unlike most disabilities, CMV is preventable. Studies in the US and France show, with proper education, mothers can reduce the chances of passing CMV to their unborn children by up to 50%, that's half the financial burden in just education alone.

According to Researchers at the Institute of medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is approximately \$200,000 per child. It costs Hawaii approximately 5 million dollars annually to care for Hawaii's children disabled by congenital CMV. "This figure is almost certainly an underestimate....." says Dr. Gail Demmler-Harrison, Director, congenital CMV disease Registry and research program.

Please pass HB 782. If ever a cause so important to implement and make a law for, it's HB 782. EVERYONE knows somone who will be pregnant and have a baby, at sometime in their life. 30,000 newborns are affected by CMV every year. Education alone would decrease this #. Early diagnosis and treatment would help those newborns infected fight this monster virus and decrease incidence of disabilities. Wouldn't you want the best treatment and care for your family and friends? I do and that's why I support HB 782

Krystal Loui

krys anu@hotmail.com



LATE

From: Frannie Girl < one2playn90@yahoo.com> Sent: Friday, February 27, 2015 2:14 AM

To: FINTestimony

Subject: HB 782

I would like to ask of you to please pass HB 782 or "kulia's Bill" thank u

Sent from Yahoo Mail for iPhone

LATE

From: southsyde maui <mauibuilt6986@gmail.com>

Sent: Friday, February 27, 2015 5:51 AM

To: FINTestimony

Subject: HB 782

Please pass HB 782.



Subject: **HB 782** – Cytomegalovirus Initiative (Kulia's Bill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing **HB 782** – **Relating to the Cytomegalovirus**.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see http://www.cdc.gov/cmv/index.html)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid by not kissing toddlers around the mouth or sharing food and utensils with them. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. These education practices have been shown in randomized clinical trials, and good evidenced based medicine reports, to reduce the risk of CMV transmission to the pregnant woman. They are also endorsed by the Centers for Disease Control at www.cdc.gov/cmv. I am a research scientist and a clinical expert with over 30 years experience treating children with congenital CMV infection and congenital CMV disease in Texas. I know their heartbreak of this life long disability first hand. And I know this infection is preventable in pregnancy.

CMV is preventable, but only if women know about it.

Sincerely,

#CMVMatters

Gail J Demmler Harrison MD
"CMVDOC"

Professor of Pediatrics, Section Infectious Diseases,
Baylor College of Medicine
Attending Physician, Infectious Diseases Service and CMV Research, Registry and Clinic,
Texas Children's Hospital

www.bcm.edu/pediatrics/cmvregistry/
www.texaschildrensblog.author/gdemmler/
cmv@bcm.edu
gdemmler@bcm.edu
gjdemmle@texaschildrens.org



From: Krystyn Aguinaldo < krystynjames@gmail.com>

Sent: Friday, February 27, 2015 1:38 AM

To: FINTestimony

Subject: Fwd: Anne Leete 782

Sent from my iPhone

Begin forwarded message:

From: Krystyn Aguinaldo < krystynjames@gmail.com >

Date: February 5, 2015 at 11:30:13 AM HST

To: Krystyn Aguinaldo <krystynjames@gmail.com>

Subject: Anne Leete 782

From: Anne Leete < annekleete@gmail.com > Date: February 3, 2015 at 10:52:17 PM HST

To: Krystyn Aguinaldo <<u>krystynjames@gmail.com</u>>

Subject: Testimony Letter

To Whom It May Concern:

I write in support of HB 782 - Kulia's Bill Re: Cytomeglovirus Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Bellati.

This bill would prevent infants and their families from suffering the life-altering and often devastating impacts of congenital CMV.

However, in order to be treated, people, and doctors, must be aware of CMV and the dangers associated with it.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. Unfortunately, only 13% of pregnant women surveyed were aware of CMV.

I am the Mother of two young boys, both born in Maui, Hawaii. I obtained regular prenatal care throughout my pregnancies from well-respected and knowledgeable doctors at Kaiser Permanente. However, none of the many doctors that I saw ever told me <u>anything</u> about CMV. While many pregnant women are aware of various birth defects or other risks to their unborn babies, I do not believe that many are aware of the seriousness of CMV or how to prevent and treat it. Despite my regular interactions with doctors throughout my

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pregnancies, I did not learn about this disease until years later when my friend's daughter was diagnosed with it at the age of five months.

Kulia was diagnosed as a result of her Mother's perseverance and dedication. However, our medical system must have something in place so that this serious disease does not go undiagnosed in another baby. We live in the wealthiest nation in the world, and have access to some of the best medical care on earth. Our doctors and nurses must work hand in hand with pregnant Mothers to educate, prevent, and treat this disease. This bill sets up a system for doing just that, thereby preventing CMV from inflicting its debilitating impacts on any more families in Hawaii.

I offer my strongest testimony in support of this bill so that every baby born in Hawaii gets the strongest possible start to life.

Mahalo, Anne Leete Attorney 808-283-7615 55 Eono Place Haiku, HI 96708 annekleete@gmail.com

District: 13

finance8-Melanie

From: Janet <pacificparadise@aol.com>
Sent: Friday, February 27, 2015 10:40 AM

To: FINTestimony Subject: Please pass HB782

Aloha

Please pass House Bill 782

God bless

Sent from my iPhone Mahalo nui loa Janet

